THE DETECTION AND TREATMENT OF DIABETES DISTRESS

By

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Abstract

The purpose of this project is to develop evidenced-based, best practice guidelines on detecting and treating diabetes distress for health care providers at Southcentral Foundation (SCF). A need was identified at SCF because health care providers do not currently screen for diabetes distress in patients with type 2 diabetes. Key findings include the importance of detecting and treating diabetes distress, critical times to screen for diabetes distress, and evidenced-based treatment options if diabetes distress is detected. It was determined that the Diabetes Distress Scale is a valid and reliable tool for health care providers to assess diabetes distress in the primary care setting at SCF. Additionally, by using the SCF approaches and processes for improvement, a Plan-Do-Study-Act cycle was created for planning and implementing sustained screening for diabetes distress in patients with type 2 diabetes. Lastly, an educational portal was designed for health care providers to better equip them for detecting and treating diabetes distress in their respective practice setting.

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Introduction

Despite national guidelines for routine screening, barriers at the provider level interfere with identifying and addressing diabetes distress in patients being treated for type 2 diabetes.[1] Barriers for providers include but are not limited to workload demands or time constraints, lack of or inadequate mental health training, and provider perceptions that mental issues are out of their realm of practice or responsibility.[1] Diabetes distress is a negative psychological reaction specific to living with diabetes which can encompass a variety of negative emotions (e.g., worry, frustration, anger, burnout) of managing type 2 diabetes.[1,2] Diabetes distress is attributed to the constant behavioral demands of managing diabetes by adhering to diet, exercise, and medication prescriptions.[2] Diabetes distress may be reported when individuals hold concern regarding potential or actual disease progression, diabetes-related complications, and/or co-morbidities.[2] Almost one-third of adults with type 2 diabetes are affected by diabetes distress.[1] The Diabetes Attitudes, Wishes and Needs second study (DAWN2) found that 45% of participants reported significant diabetes distress, though only 24% were asked about the debilitating disorder by their health care team.[3] The 2020 American Diabetes Association (ADA) Standards of Care in Diabetes recommends routine monitoring for diabetes distress in patients with diabetes, especially when treatment goals are not met and/or when diabetes-related complications arise.[3] The ADA has also partnered with the American Psychiatric Association in an effort to increase the number of professionals with knowledge of diabetes-related psychosocial factors, including diabetes distress.[4] The importance of addressing diabetes distress is that it can impair self-management (e.g., medication taking behaviors, decreased self-efficacy) and is highly correlated with negative diabetes outcomes (e.g., higher A1c, poor nutrition and exercise behaviors) thus impacting the overall health and quality of life of patients and increasing medical costs.[3,4]

Background and Significance

Diabetes distress is not depression, but rather a direct reflection of the burden of diabetes; it is the subjective experience of that burden.[4] The ADA Standards of Medical Care in Diabetes defines diabetes distress as "significant negative psychological reactions related to emotional burdens and worries specific to an individual's experience in having to manage a severe, complicated, and demanding chronic disease."[3 (pg S54)] There is no official medical diagnosis for diabetes distress and there is minimal research on how to measure diabetes distress.[4] A variety of questionnaires have been developed for the assessment of diabetes-related emotional burden. Problem Areas in Diabetes (PAID) Questionnaire and the Diabetes Distress Scale (DDS) are two recommended instruments used to measure diabetes distress.[1] The questionnaires give insight to the patient's perceived difficulty related to diabetes management and the negative emotions associated with living with diabetes.[1] In addition to providing patients with questionnaires to better evaluate how diabetes affects their lives, providers can verbally inquire about attitudes and issues associated with managing diabetes.

Health care providers should inform patients with type 2 diabetes about diabetes distress, so patients can advocate for their mental health and address their emotional needs.[1] When diabetes distress is detected, patients should be referred for diabetes education to determine what areas of self-care are most important to them and how to best manage their diabetes.[1,3] Diabetes Self-Management Education and Support (DSMES) is an evidenced-based program that offers people with diabetes the information and strategies to make sound decisions regarding diabetes self-care.[1] Participation in DSMES may improve hemoglobin A1c by 0.6%, which is similar to many medications without the side effects.[5] Furthermore, greater Alc improvements was linked with DSMES services greater than 10 hours.[5]

Southcentral Foundation (SCF) values health care centered around the patient with a vision of physical, mental, emotional and spiritual wellness for their population. At this time there are no best practice guidelines at SCF on how to detect and/or treat patients who are suspected of diabetes distress. Developing an evidenced-based system of care for patients with diabetes distress will allow health care providers to better detect and treat the condition in patients who have type 2 diabetes.

Research Goal and Objectives

Goal: Develop best practice guidelines for health care providers to detect and treat diabetes distress.

Objectives:

1. Determine evidence-based, best practices for the detection of diabetes distress.
2. Determine evidence-based, best practices for the treatment of diabetes distress.
3. Analyze if and how SCF healthcare providers are detecting diabetes distress.
4. Develop a Plan-Do-Study Act (PDSA) using the READI model and Model for Improvement that the SCF Improvement Specialist team could implement as a pilot study in primary care for detecting diabetes distress, if desired.
5. Develop an educational portal for health care providers on diabetes distress.

Literature Review

Evidenced-Based Practices for the Detection of Diabetes Distress

In 2001 a landmark, large cross-national study entitled the *Diabetes Attitudes, Wishes and Needs (DAWN)* highlighted that psychosocial problems and barriers exist across countries and strategies are needed to improve current diabetes care for patients and providers.[6] The countries included in the study were Australia, France, Germany, India, Japan, Netherlands, Poland, Scandinavia (Denmark, Norway, Sweden), Spain, United Kingdom (UK) and the United States of America (USA). Of note, the DAWN study included patients with type 1 and type 2 diabetes; however, data and information provided in this literature review is for type 2 diabetes only. The DAWN study confirmed that people with diabetes commonly experience diabetes distress and poor psychological well-being (41%) such as anxiety, worry, and fear.[6] However, in the past 5 years only 12% of patients received treatment for these psychological problems.[6] The research also illustrates that providers are aware of the possibility of diabetes distress in patients and that psychological issues (including depression, anxiety, stress, and burnout) are related to negative disease outcomes. Yet providers experience barriers, such as a lack of confidence to assess psychological issues and inadequate resources for their patients, that prevent them from addressing psychological needs and thus lowering the quality of diabetes care.[6] Psychosocial factors such as attitudes about diabetes expectations for diabetes management and outcomes, available resources (social, emotional, and financial), psychological states, and health literacy and numeracy, should be monitored as they create a barrier to diabetes self-care and positive outcomes.[7] Health care models that integrate psychosocial services are essential for health care professionals to provide best possible care.[6]

Following the original DAWN study, the 'DAWN Call to Action' was created to engage multiple stakeholders (including people with diabetes, family members, and healthcare professionals) to support a paradigm shift resulting in patient-centered, integrated care leading to active management of diabetes.[8] The 'DAWN Call to Action' identified six areas for improvement surrounding diabetes care at the individual, healthcare organization/community, and policy levels: "(1) raising awareness of the person with diabetes (PWD) perspective, (2) empowerment of PWD through information and education, (3) training of healthcare professionals, (4) development of innovative tools to deliver PWD support, (5) improvement of guidelines/policies for person-centered care, and (6) translational research into delivery of person-centered diabetes care."[8 (pg 181).]

A decade after the original DAWN study took place, a follow up study called the DAWN2 study initiative was undertaken to explore further avenues identified by stakeholders for improving diabetes care and management. An objective of the DAWN2 study was to identify best practices to facilitate change that improve outcomes for people with diabetes. Participants were surveyed on topics including diabetes impact and burden. Diabetes distress was assessed using the PAID questionnaire. Based on feedback from participants in the DAWN2 study, 45% reported significant diabetes distress, though only 24% were asked about the debilitating disorder by their health care team.[9] Despite advances in medical treatment and therapeutic options for diabetes, the DAWN2 study reveals that diabetes care remains insufficient because many people living with diabetes have unmet treatment goals.[9] To date, the DAWN2 study results still need to be transformed into actions by stakeholders to improve self-management and psychosocial support for patients with diabetes.[9]

The ADA (American Diabetes Association) Standards of Medical Care 2020 provides evidence-based guidelines for psychosocial assessment and care of individuals with diabetes and their families. The guidelines recommend that important screening opportunities for psychosocial issues such as diabetes distress occur at diabetes diagnosis, routinely scheduled diabetes management visits, during hospitalizations, and during transitions in care (e.g., pediatric to adult care teams).[3] If barriers to achieving quality of life or self-management are evident during these times, and particularly when treatment goals are not met and/or when complications arise, the diabetes care team should consider screening for possible psychosocial issues such as diabetes distress.[3] Evidence found that patients are more susceptible to psychosocial issues at diagnosis, transitions in disease status or treatment needs, and at the onset of diabetes-related complications.[3] Inquiring about social determinants (e.g., loss of job, family related stressors) during routine care is key since they can alter an individual's ability to manage the chronic health condition.[3] Patient's attitude about diabetes, expectation for diabetes care and outcomes, access to resources, (including financial, social, and emotional resources) and psychiatric history are other factors known to impact self-care and health outcomes.[3] Psychosocial assessment and care should be addressed using a relationship-based, patient-centered, and evidence-based framework.[7]

When a person is initially diagnosed with diabetes it is important for providers to inform the patient about diabetes distress.[3] Understanding the condition can validate a patient's negative psychological reactions if they experience such emotions and prompt them to seek additional assistance.[3] During routine follow up visits, providers should inquire if patients can identify existing barriers to self-care to manage their diabetes.[3] A nonjudgmental approach to patients has been shown to decrease resistance in disclosing problems with self-management.[7] When patients

exhibit negative responses, providers can remind patients about diabetes distress, the related symptoms, and treatment options.[3]

There are considerations in the detection of diabetes distress which are barriers that providers experience. The DAWN2 study highlighted concerns of healthcare professionals regarding the delivery of diabetes care, self-management, and training.[10] Respondents indicated a variety of major improvements are needed, including but not limited to, availability of DSME (61%), resources for the provision of psychosocial support and care (63%), and communication between patients with diabetes and the diabetes care team (56%).[10] The DAWN2 study also revealed that over half of healthcare professionals (52%) had inquired about how diabetes impacts their patients' lives, but 13% reported insufficient resources to offer their patients who are emotionally distressed.[10] Sixty percent of healthcare professionals also recognize the need for patients to take a more active role in self-management activities such as physical activity (93%), healthy eating (91%), maintaining a healthy body weight (90%), self-monitoring of blood sugar (62%), and addressing diabetes-related emotions (63%).[10] Strategies to address these barriers at the provider level include participating in mental health training, using evidenced-based guidelines to deliver diabetes care, and identifying ways to address and manage mental health issues during routine diabetes care.[1] The DAWN2 provides the best evidence on the views and needs of stakeholders who are involved in diabetes care. It is clear that more effective communication and collaboration is needed between people with diabetes, support persons of people with diabetes, and the diabetes care team to instill confidence and engagement in the overall management of diabetes.[10]

The ADA selected the following measures as appropriate for the evaluation of diabetes distress in the clinical setting: Problems Areas in Diabetes (PAID), Diabetes Distress Scale

(DDS), PAID-Pediatric Version (PAID-Peds), PAID-Teen Version, PAID-Parent Revised version (PAID-PR).[7] This literature review will focus on the PAID and DDS scale as these two are the most commonly utilized tools that measure diabetes distress and are validated for adults with type 1 and type 2 diabetes . The PAID-Peds and PAID-Teen version are not validated for adults but rather measure perceived diabetes burden for youth ages 8-17 years with type 1 diabetes, and adolescents ages 11-19 with diabetes, respectively.[7]

The PAID was developed in 1995. It consists of 20 items evaluating diabetes-related problems including psychological (e.g., emotional) and psychosocial (e.g., treatment and food-related problems and lack of social support).[11] A five-point Likert scale is used to rate the severity of each problem. Scores can range from 0 to 100 with scores 40 or higher indicating more severe distress in which treatment may be warranted.[11]

The DDS was developed ten years later in 2005 to make up for limitations of the PAID Scale.[11] The DDS contains 17 items evaluating diabetes-specific problems. A six-point Likert scale rates the severity of the problems listed.[11] Scores are averaged to a total score between 1 and 6 with higher values signifying greater distress. A score of 3 or higher is considered clinically meaningful distress levels according to the DDS17 scoring sheet.[11] The DDS is based on four subscales which include evaluation of emotional burden, physician-related distress, regimen-related distress, and diabetes-related interpersonal distress.[11,12] Screening for diabetes distress can be initiated with a two-item questionnaire (DDS2) to detect potential problem areas for people living with diabetes, specifically in the last month: 1) Feeling overwhelmed by the demands of living with diabetes, 2) Feeling that I am often failing with my diabetes routine.[13] If positive findings are discovered (average of the 2 screening items is ≥3, or whose sum is

≥6), the DDS17 can be administered to understand the context of distress and provide health care professionals direction for care.[13]

A study that compared the properties of the two most common assessment tools for diabetes distress (PAID and DDS), found that both questionnaires inquire about negative emotions with diabetes, lack of social support, and worry for future complications.[11] The PAID scale also addresses issues regarding diet, complications such as hypoglycemia or dysglycemia, and a variety of emotional issues such as diabetes burnout and lack of diabetes acceptance.[11] In contrast, the DDS targets motivational and behavioral issues regarding self-management and physician-related distress.[11] Both scales were assessed for their relationship to the following criteria of interest: diabetes-related coping, health-related quality of life, depressive symptoms, self-care, and metabolic control.[11] It was found that the DDS was significantly related to all criteria of interest and the PAID to most criteria.[11] Measure of distress on the PAID scale was significantly associated with poorer coping styles, elevated depressive symptoms, and decreased quality of life, whereas the DDS revealed significantly greater negative associations with elements of diabetes self-care and metabolic outcomes.[11] Although the study presents many strengths, such as reliable and validated assessment tools, limitations also need to be considered. Limitations of this study included a majority of study participants had type 1 diabetes, most were treated with insulin (even type 2 participants), and the location of recruitment influenced the sample characteristics since it was a referral center for problems with diabetes treatment and control.[11] Therefore, this population sample may not represent typical patients receiving diabetes care in primary care settings. In summary, Schmitt, et.al., conclude that both the PAID and DDS are practical psychometric tools that have shown to provide similar results.[11] However, reasons to choose one tool over the other may be indicated. For instance,

preferences for the DDS scale should be considered when aspects of diabetes distress are to be assessed separately; when assessing associations between diabetes distress and self-care and metabolic outcomes; and if cross-cultural comparisons of distress is intended.[11] The PAID scale may be more appropriate if a variety of diabetes related concerns is to be evaluated; assessing the impact of diabetes distress on quality of life or depression; and if a global comparison of distress of people with different types of diabetes is desired.[11]

At Southcentral Foundation (SCF) there are currently no formal screening measures utilized to detect diabetes distress. SCF patients are screened for other psychosocial issues such as depression using the PRIME-MD Patient Health Questionnaire (PHQ) and/or PHQ-9. Patients can also be referred to integrated behavioral health consultants or integrated physiatrists when psychosocial or psychological issues are apparent or disclosed. Incorporating routine monitoring of diabetes distress into the primary care setting at SCF can allow the diabetes care team to fully address patients' needs, concerns, and desires regarding management of their condition. Based on the research that has been analyzed, using the DDS (2 item and 17 item scales) can better equip providers with diabetes distress detection tools to guide necessary intervention.

Evidenced-Based Practices for the Treatment of Diabetes Distress

Diabetes distress is a common negative psychological reaction that people with diabetes experience, which can encompass a variety of negative emotions (e.g., worry, frustration, anger, burnout) of managing type 2 diabetes.[1,2] Diabetes distress is attributed to the constant behavioral demands of managing diabetes by adhering to diet, exercise, and medication prescriptions.[2] Diabetes distress may also be reported when individuals hold concern regarding potential or actual disease progression, diabetes-related complications, and/or co-morbidities.[2] Diabetes distress can impact treatment outcomes, quality of life, and other clinical, psychosocial, and

behavioral aspects of diabetes, thus emphasizing the importance of detection and treatment interventions. Over the years, a variety of questionnaires have been developed for the assessment of diabetes-related emotional burden. The Problem Areas in Diabetes (PAID) questionnaire and the Diabetes Distress Scale (DDS) are the two most commonly used instruments to measure diabetes distress.[1] The questionnaires give insight to the patient's perceived difficulty related to diabetes management and the negative emotions associated with living with diabetes.[1] In addition to providing patients with questionnaires to better evaluate how diabetes affects their lives, providers can verbally inquire about attitudes and issues associated with managing diabetes. When diabetes distress is detected, patients should be referred to Diabetes Self-Management Education and Support (DSMES) services to address the barriers to self-care and contributors to distress.[3]

DSMES services have shown to provide multiple benefits regarding clinical, psychosocial, and behavioral elements of diabetes. The benefits include improved healthful behaviors such as an improved diet, increased exercise, better coping strategies, and enhanced self-efficacy.[3,5,14] Improved clinical management was reported in multiple studies such as the lowering of A1c by 1% in people with type 2 diabetes; reduced onset and/or advancement of disease complications; decreased hospitalizations, readmission rates, and medical costs.[3,5,14] Other positive impacts of DSMES include reduced diabetes distress and improved quality of life and self-management behaviors.[3,5,14] The role of the DSMES team is to support patients by facilitating goal setting and adjusting communication based on participant needs for DSMES services.[5] By assessing patient needs and concerns, providers of DSMES can provide information and skills that encourage successful coping and self-management.[5] Evidence shows that there are four critical times to assess, provide, and adjust DSMES—at diagnosis, annually,

when complications occur, and during transitions in care.[5] The first critical point that the diabetes team should consider a referral to DSMES is when an individual is newly diagnosed with type 2 diabetes.[14] Nutrition and emotional health should be addressed through provider education and/or a referral to a registered dietitian nutritionist for medical nutrition therapy and a mental health professional for emotional health if necessary.[14] Providers should assess patients annually for education, nutrition, and emotional needs.[14] The following may be additional reasons to consider referral to DSMES: to enhance diabetes knowledge, skills, and behaviors; change in diabetes related behaviors such as diet, physical activity, or medication; treatment goals above target (e.g., A1c); long standing diabetes without prior education; dysglycemia; weight or other nutrition related concerns; new life circumstance and demands; planning for pregnancy or pregnant, or for support to attain or maintain healthful behaviors and outcomes.[14] A third critical point to consider DSMES services is "when new complicating factors influence self-management."[14] (pg 73) Changes that may constitute a referral include diabetes complications such as heart and kidney disease; complicated or intensified medication regimen; physical limitations; psychosocial issues including anxiety and depression; and altered access to basic needs such as food; and financial stability. Finally, the fourth critical point is when transition in care occurs.[14] This may include changes in the patient's living situation, health care team members, insurance changes that alter care provided, and age-related circumstances that impact cognition, self-care, etc.[14] While the initial referral to DSMES is important, it is not adequate for patients to maintain a lifetime of effective self-management.[5] Instead, ongoing support is needed to sustain the skills, knowledge, and behaviors developed during DSMES.[5] The following diabetes self-care topics are the most helpful during DMSES to determine participants' needs and concerns: "diabetes pathophysiology and treatment options; healthy eating, physical activity; medication usage; monitoring and using

patient-generated health data; preventing, detecting, and treating acute and chronic complications; healthy coping with psychosocial issues and concerns; and problem solving."[5 (pg 39)] Evidence also shows that if self-care does not improve after diabetes education, patients should be referred to a behavioral health provider for assessment and treatment.[3]

As noted in the Evidenced Based Practiced in the Detection of Diabetes Distress section above, the landmark study titled the *Diabetes Attitudes, Wishes and Needs (DAWN)* found that psychosocial problems and barriers exist and strategies are needed to improve current diabetes care for patients and providers.[6] A follow up study called the DAWN2 occurred a decade later to explore further avenues identified by stakeholders for improving diabetes care and management.[8] The holistic approach to the DAWN2 study illustrated that the majority of people (80%) that participated in any education program found it 'somewhat helpful' or 'very helpful.'[9] Among U.S. participants that engaged in DSMES services, most people with diabetes and family members found it to be helpful (78 and 70%, respectively).[15] Additionally, minority groups studied in the U.S. experience greater diabetes distress and burden yet remain an underserved population.[15] An assessment following the DAWN2 study analyzed the differences in psychological outcomes (e.g., well being, quality of life, diabetes impact, diabetes distress, and diabetes empowerment) for a separate U.S. minority sample from a variety of ethnic backgrounds including White non-Hispanics, African Americans, Hispanics, and Chinese Americans.[16] After controlling for socioeconomic disparities such as educational background and income, it was found that minority groups experience more positive psychological outcomes in regard to diabetes for all categories previously mentioned, except diabetes distress compared to White non-Hispanics.[16] Research has shown that ethnic minority groups experience more health

issues and are at greater risk for some diabetes related complications.[16] This is important as diabetes distress can negatively impact diabetes self- care and outcomes.

Research by Zagarins, et.al., revealed that change in diabetes distress from baseline to 6 months was significantly associated with change in glycemic control ($P < 0.01$).[17] The study population saw an average 10-point decrease on the PAID scale for diabetes distress after a DSME intervention, which was associated with a 0.25% reduction in HbA1c.[17] The study also demonstrated significant improvement in self-care behaviors and treatment satisfaction following DSME intervention.[17] The study presumed that DSME improved diabetes distress and glycemic control due to the collaborative nature of the intervention and development of problem solving and coping skills that can address emotions related to living with diabetes.[17]

Provider referral and patient attendance to DSMES presents its own barriers. Challenges that an individual may experience that prevent participation in DSMES services include socioeconomic or cultural reasons, schedules, health insurance restrictions, lack of knowledge regarding the importance of participating, and the health care team may not encourage or refer to DSMES services.[5] Similarly, health care providers may not understand the necessity and effectiveness of DSMES, which impacts the referral rates. Providers also may not be informed of when and how to refer to DSMES or may lack access to such resources and services.[14] Based on provider feedback collected in past studies, providers' needs and concerns must be acknowledged and addressed in order to improve the clinical and psychosocial issues of people living with diabetes.

Resources to treat diabetes distress are offered at SCF. DSMES services are offered at least once each month and integrated care team members (e.g., behavioral health consultants, dietitians, and pharmacists) are staffed within primary care as needed. As the literature reports,

DSMES attendance rates can be negatively impacted by a lack of referrals from providers. This barrier has been addressed with health care providers at SCF in the past by providing 1) an informative presentation about the four critical times to assess and refer for education, 2) focus areas of DSMES at each of these times, 3) evidenced-based benefits of DSMES, and 4) how to refer within SCF.

It is important that providers are up to date with screening and treatment recommendations for psychosocial issues such as diabetes distress because patients with type 2 diabetes may experience negative emotions regarding living with and managing diabetes at some point. Integrated behavioral health consultants see many psychosocial issues such as anxiety and depression and health care providers should understand the impact of diabetes distress as a potential barrier to self-care and health outcomes. Asking patients how diabetes impacts their lives or about negative implications in managing their diabetes can open communication and build a relationship between patients and providers. This patient-centered approach improves diabetes care by addressing patients' needs, concerns, and wishes and allows patients to implement problem solving strategies in diabetes self-care and management.

Performance Improvement: PDSA

Southcentral Foundation (SCF) has developed its own approach for change and improvement in patient care called the READI model.[18] The READI model has the following 5 phases: reaching understanding, establish relationship, assessment of gaps/possibilities, development and implement action plan, and integrate solutions and evaluate results.[18] The first phase, reaching understanding, involves an improvement specialist/advisor connecting with relevant stakeholders (employees and/or leadership) after identifying a necessary improvement, need, or goal.[18] During the second phase, the improvement specialist/advisor establishes a relationship with appropriate

stakeholders and creates the basis for moving forward with improvements and initiatives.[18] Phase three encompasses the improvement specialist/advisor and relevant stakeholders assessing gaps and possibilities based on current circumstances and end goals while evaluating what is working well in the current state.[18] Phases four and five involve the improvement specialist/advisor and relevant stakeholders to plan, test, and implement the action plan, followed by an evaluation of the results and the processes of sustaining improvements.[18]

The second part of SCF's improvement approach is utilizing the Model for Improvements as a basis for planning, testing, and implementing quality improvements.[18] This involves two parts called the "thinking" part and the "doing" part.[18] The thinking part contains questions that guide the planning process for the improvement plan. The thinking parts asks three questions: what are we trying to accomplish; how will we know that a change is an improvement; and what change can we make that results in improvement?[5] The doing part is the guide for implementation called Plan, Do, Study, Act (PDSA) for both pilot testing and sustained changes.[18]

By using the SCF approaches and processes for improvement, the following will help to provide a Model for Improvement (aim, measure, ideas) and PDSA for detecting and treating diabetes distress in patients with type 2 diabetes.

Aim: SCF primary care providers will begin screening for diabetes distress routinely. The Diabetes Distress Scale (DDS) 2-item questionnaire will be given to patients annually if their diabetes management is at goal, and biannually if the patient's treatment targets are not met and/or if diabetes related complications arise. If positive findings are discovered, the 17-item DDS scale can be administered to understand the context of distress.

Measures: After a predetermined amount of time, an improvement specialist/advisor will collect the DDS questionnaires (2-item and 17-item) from each team in order to create a

summary of how many patients complete the questionnaire in comparison to how many total diabetes care visits were completed by each primary care provider (PCP).

Ideas: The electronic health record (EHR) would be set up to indicate that the patient is due for a questionnaire at the one year or six-month mark. At any point providers may offer the 2-item DDS questionnaire if they identify unmet treatment targets or at the onset of diabetes complications. In addition, an online educational portal will be available to health care providers involved with diabetes care to help them understand the importance of detecting and treating diabetes distress and to access resources for them and their patients.

Plan: After a predetermined start date is established, every patient that sees their PCP for routine diabetes care will be asked to complete a 2-item DDS questionnaire upon their appointment check in. The questionnaire will be collected and scored by the team's certified medical assistance and delivered to the PCP prior to the visit with the patient. If positive findings are discovered, the 17-item DDS scale can be administered to understand the context of distress. If a patient has diabetes distress based on findings from the DDS2 and the DDS17, the provider should review the subscale(s) that are positive for diabetes distress (sums 3 or higher), and inquire further to begin a conversation regarding the patient's overall feelings about managing diabetes. Additionally, the patient should be referred to appropriate treatment options provided at SCF such as integrated behavioral health consultant, dietitian, or pharmacist and/or be registered for Diabetes Self-Management Education and Support services. If the patient does not have diabetes distress, the patient will be rescreened in one year or at follow up visits if treatment goals are not met and/or if diabetes related complications arise. Each DDS questionnaire will be scanned into the patient's EHR. Once the plan is implemented, health care providers will gain a better understanding of barriers patients are experiencing that inhibit their ability to self-manage

their diabetes. Implementation of routine screening for diabetes distress may also increase referrals to available resources including integrated care team members and diabetes education services.

Do: At this stage, screening for diabetes distress is implemented for appropriate appointment types. Initially, this phase would involve the PCP teams participating in the pilot test prior to rolling the solution out to all of primary care.

Study: Since zero DDS questionnaires are currently distributed, the analysis would involve assessing the number of screeners completed compared to the total number of diabetes care visits with each PCP for a predetermined amount of time. Other analyses should include how many patients declined filling out the screener, how many patients missed their appointments for diabetes care, and other gaps associated with screening if not all patients are screened for diabetes distress who meet criteria. Additionally, if a patient has diabetes distress, the patient's EHR should note what treatment options were discussed and/or what referrals were placed, if any. In an attempt to ensure patients are screened for diabetes distress, an organizational goal should be established based on the number of patients with diabetes for whom a provider provides diabetes care.

Act: The improvement specialist/advisor and PCP teams involved in the pilot test should gather to discuss gaps and possibilities from the analysis in order to sustain screening for diabetes distress in primary care.

Moving forward with this quality improvement project at SCF would involve meeting with an improvement specialist team member to determine logistics of implementing the pilot study. The developed PDSA cycle would be reviewed and modified as needed to determine feasible execution efforts. Communicating the reason for the project to PCP teams apart of the pilot study

would be a necessary step because providers need to understand the importance of screening for diabetes distress in the primary care setting.

Methods

Study Design

The study design for this project is quality improvement research. Quality improvement research is "the design, development and evaluation of complex interventions aimed at the redesign of health care systems to produce improved outcomes."[19 (pg 1)] A need was determined at Southcentral Foundation (SCF) for patients with type 2 diabetes. Currently patients are not being screened for diabetes distress as suggested by the research, thus potentially neglecting opportunities for treating this set of conditions. The 6S search strategy was employed to find evidenced-based best practices for the detection and treatment of diabetes distress. Based on the American Diabetes Association's selected measures for the evaluation of diabetes distress, all relevant, validated tools were identified and the tool best suited for SCF was selected. Of the five validated tools that were identified and further investigated, the Diabetes Distress Scale (DDS) was determined to fit the SCF population best. The DDS scale may be helpful in primary care when assessing associations between diabetes distress and self-care and metabolic outcomes.[11]

When diabetes distress is detected, patients should be referred to appropriate diabetes education to address the barriers to self-care and contributors to distress..[3] Nutrition and emotional health should be addressed during education and/or a referral to a registered dietitian nutritionist for medical nutrition therapy and a mental health professional for emotional health if necessary.[14]

Once an appropriate tool was chosen the SCF Improvement Overview booklet was reviewed. The SCF Improvement Overview booklet is a resource for Improvement Advisors and Improvement Specialists for facilitating improvement and innovation across SCF. As mentioned, "the booklet defines the way SCF approaches and manages improvement and innovation, the

SCF improvement process and framework, and the specific tools and methods used to assist in improvement efforts."[18 (pg 2)] Details of the SCF approach for change and improvement, called the READI model, and general framework for planning and implementing quality improvement, called the Model for Improvement, were examined. A Model for Improvement using the Plan, Do, Study, Act (PDSA) was constructed for health care providers to detect and treat diabetes distress in primary care, if desired for utilization.

Next, in order to educate providers who may not have the background, understanding, or knowledge of diabetes distress, an educational portal was created. Using the University of Alaska Anchorage's (UAA) electronic portfolio service called eWolf, an account was created to begin the development of an educational portal. The educational portal system is for health care providers at SCF to access to aid them in the detection and treatment of diabetes distress. Separate tabs were created to house information on the following: evidenced-based best practices for the detection and treatment of diabetes distress; three educational webinars on the overview of diabetes distress, detection of diabetes distress and treatment of diabetes distress; best tool for detecting diabetes distress at SCF; resources for treating diabetes distress; handouts for patients, and the PDSA summary for implementing detection and treatment of diabetes distress into primary care. This educational portal is an easily accessible tool that could be shared with SCF healthcare providers to gain a deeper understanding on this topic area, if desired.

IRB Approval

Institutional Review Board (IRB) approval was not needed for this project. To ensure IRB approval was not needed, a Human Subjects Research (HSR) Determination Request Form was sent to the UAA IRB. An email was returned stating "The University of Alaska Anchorage

IRB has determined this project does not meet the definition of human subject research under the purview of the IRB according to federal regulations." See Appendix for official letter from IRB.

Results

Outcomes of this project include evidenced-based best practices for the detection and treatment of diabetes distress, determining a need at SCF to screen for diabetes distress at routine diabetes care visits, and development of an improvement plan using a Plan-Do-Study Act (PDSA) cycle and a provider educational portal. Key findings include the importance of detecting and treating diabetes distress, critical times to screen for diabetes distress, and evidenced-based treatment options if diabetes distress is detected. It was determined that the Diabetes Distress Scale is a valid and reliable tool for health care providers to assess diabetes distress in the primary care setting at SCF. Additionally, by using the SCF approaches and processes for improvement, a PDSA cycle was created for planning and implementing sustained screening for diabetes distress in patients with type 2 diabetes. Lastly, an educational portal was designed for health care providers to better equip them for detecting and treating diabetes distress in their respective practice setting.

Strengths and Limitations

Although some research articles included subjects with type 1 diabetes, the focus of the project was on patients with type 2 diabetes.

Conclusions and Recommendations

A significant part of diabetes care is detecting and treating diabetes distress. Health care providers need to understand the importance of screening for diabetes distress and what steps they can take if a patient presents with signs of diabetes distress. An opportunity exists to detect and treat diabetes distress at SCF in the primary care setting. Incorporating routine monitoring of diabetes distress can allow the diabetes care team to fully address patients' needs, concerns, and desires regarding management of their condition. It was found that the Diabetes Distress Scale can better equip providers for detection of diabetes distress at recommended screening opportunities and when psychosocial factors are identified. SCF is currently equipped with recommended treatment options that include DSMES service and integrated care team members such as an RDN and mental health professional. Finally, an educational portal has been developed for health care providers to access relevant information regarding diabetes distress, if desired.

Dietetics and Nutrition Practice Implications

At this time there are no best practice guidelines at SCF on how to detect and/or treat patients who are suspected of having diabetes distress. The importance of addressing diabetes distress is that it can impair self-management and is highly correlated with diabetes outcomes thus impacting the overall health and quality of life of patients and increasing medical costs. As the research indicated, diabetes distress is attributed to the constant behavioral demands of managing diabetes by adhering to various prescriptions, such as a diet prescription.[2] Based on findings from the research, it is necessary and feasible for health care providers at SCF to screen for diabetes distress in the primary care setting. The 2 item and 17 item DDS can be a quick and easy tool for both patients and providers in an effort to screen for diabetes distress. This can be accomplished by pilot testing the PDSA cycle in an effort to plan and implement sustained screening for diabetes distress in patients with type 2 diabetes. Implementing an evidenced-based system of care for patients with diabetes distress will allow health care providers to better detect and treat the condition in patients who have type 2 diabetes.

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Appendices

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DATE:	January 8, 2020
TO:	Kylie Viens
FROM:	University of Alaska Anchorage IRB
PROJECT TITLE:	[1508877-1] The Detection and Treatment of Diabetes Distress
SUBMISSION TYPE:	New Project
REVIEW TYPE:	IRB Chair / Administrative
ACTION:	DETERMINATION OF NOT HUMAN SUBJECTS RESEARCH
DECISION DATE:	January 8th 2020

Thank you for your submission of New Project materials for this research study. The University of Alaska Anchorage IRB has determined this project does not meet the definition of human subject research under the purview of the IRB according to federal regulations.

We will retain a copy of this correspondence within our records.

If you have any questions, please contact Robert Boeckmann at (907) 786-1793 or rjboeckmann@alaska.edu. Please include your project title and reference number in all correspondence with this office.

Robert J. Boeckmann, Ph.D
Chair, Institutional Review Board

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DDS

THE DIABETES DISTRESS SCREENING SCALE

DIRECTIONS: Living with diabetes can sometimes be tough. There may be many problems and hassles concerning diabetes and they can vary greatly in severity. Problems may range from minor hassles to major life difficulties. Listed below are 2 potential problem areas that people with diabetes may experience. Consider the degree to which each of the 2 items may have distressed or bothered you DURING THE PAST MONTH and circle the appropriate number.

Please note that we are asking you to indicate the degree to which each item may be bothering you in your life, NOT whether the item is merely true for you. If you feel that a particular item is not a bother or a problem for you, you would circle "1". If it is very bothersome to you, you might circle "6".

	Not a Problem	A Slight Problem	A Moderate Problem	Somewhat Serious Problem	A Serious Problem	A Very Serious Problem
1. Feeling overwhelmed by the demands of living with diabetes.	1	2	3	4	5	6
2. Feeling that I am often failing with my diabetes routine.	1	2	3	4	5	6

DDS

DIRECTIONS: Living with diabetes can sometimes be tough. There may be many problems and hassles concerning diabetes and they can vary greatly in severity. Problems may range from minor hassles to major life difficulties. Listed below are 17 potential problem areas that people with diabetes may experience. Consider the degree to which each of the 17 items may have distressed or bothered you DURING THE PAST MONTH and circle the appropriate number.

Please note that we are asking you to indicate the degree to which each item may be bothering you in your life, NOT whether the item is merely true for you. If you feel that a particular item is not a bother or a problem for you, you would circle "1". If it is very bothersome to you, you might circle "6".

	Not a Problem	A Slight Problem	A Moderate Problem	Somewhat Serious Problem	A Serious Problem	A Very Serious Problem
1. Feeling that diabetes is taking up too much of my mental and physical energy every day.	1	2	3	4	5	6
2. Feeling that my doctor doesn't know enough about diabetes and diabetes care.	1	2	3	4	5	6
3. Feeling angry, scared, and/or depressed when I think about living with diabetes.	1	2	3	4	5	6
4. Feeling that my doctor doesn't give me clear enough directions on how to manage my diabetes.	1	2	3	4	5	6
5. Feeling that I am not testing my blood sugars frequently enough.	1	2	3	4	5	6
6. Feeling that I am often failing with my diabetes routine.	1	2	3	4	5	6
7. Feeling that friends or family are not supportive enough of self-care efforts (e.g. planning activities that conflict with my schedule, encouraging me to eat the "wrong" foods).	1	2	3	4	5	6
8. Feeling that diabetes controls my life.	1	2	3	4	5	6

	Not a Problem	A Slight Problem	A Moderate Problem	Somewhat Serious Problem	A Serious Problem	A Very Serious Problem
9. Feeling that my doctor doesn't take my concerns seriously enough.	1	2	3	4	5	6
10. Not feeling confident in my day-to-day ability to manage diabetes.	1	2	3	4	5	6
11. Feeling that I will end up with serious long-term complications, no matter what I do.	1	2	3	4	5	6
12. Feeling that I am not sticking closely enough to a good meal plan.	1	2	3	4	5	6
13. Feeling that friends or family don't appreciate how difficult living with diabetes can be.	1	2	3	4	5	6
14. Feeling overwhelmed by the demands of living with diabetes.	1	2	3	4	5	6
15. Feeling that I don't have a doctor who I can see regularly enough about my diabetes.	1	2	3	4	5	6
16. Not feeling motivated to keep up my diabetes self management.	1	2	3	4	5	6
17. Feeling that friends or family don't give me the emotional support that I would like.	1	2	3	4	5	6

DDS17 SCORING SHEET

INSTRUCTIONS FOR SCORING:

The DDS17 yields a total diabetes distress scale score plus 4 sub scale scores, each addressing a different kind of distress. To score, simply sum the patient's responses to the appropriate items and divide by the number of items in that scale. The letter in the far right margin corresponds to that item's subscale as listed below. **We consider a mean item score of 3 or higher (moderate distress) as a level of distress worthy of clinical attention.** Place a check on the line to the far right if the mean item score is ≥ 3 to highlight an above-range value.

We also suggest reviewing the patient's responses across all items, regardless of mean item scores. It may be helpful to inquire further or to begin a conversation about any single item scored 3 or higher.

Total DDS Score:

a. Sum of 17 item scores. _____
b. Divide by: 17
c. Mean item score: _____ ≥ 3 ____

A. Emotional Burden:

a. Sum of 5 items (1, 3, 8, 11, 14) _____
b. Divide by: 5
c. Mean item score: _____ ≥ 3 ____

B. Physician-related Distress:

a. Sum of 4 items (2, 4, 9, 15) _____
b. Divide by: 4
c. Mean item score: _____ ≥ 3 ____

C. Regimen-related Distress:

a. Sum of 5 items (5, 6, 10, 12, 16) _____
b. Divide by: 5
c. Mean item score: _____ ≥ 3 ____

D. Interpersonal Distress:

a. Sum of 3 items (7, 13, 17) _____
b. Divide by: 3
c. Mean item score: _____ ≥ 3 ____